



Developmental Disabilities Planning Council

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2022 - 2026 State Plan



Advocacy · Innovation · Inclusion

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Developmental Disabilities Planning Council

What We Do

The mission of the New York State (NYS) Developmental Disabilities Planning Council (DDPC) is to enhance the lives of New Yorkers with Intellectual and Developmental Disabilities (IDD) and their families/caregivers through programs that promote self-advocacy, participation and inclusion in all facets of community life.

Our State Plan

Our work is guided by a five-year plan called the State Plan.

The 2022-2026 State Plan addresses changing state and national policies, is guided by stakeholder input and acknowledges shifts in IDD services. Our State Plan consists of goals and objectives that the NYS DDPC plans to work toward over the next five years.

State Plan Development: Public Input

What goes into developing the State Plan?

The NYS DDPC spent two years conducting research, including gathering public input about the barriers that people IDD and their families' experience in NYS. Some of the strategies used to collect public input are outlined below.

Outreach and Engagement Strategies



Online Survey

The online survey was distributed through multiple listservs and social media accounts resulting in 984 responses, representing a diverse set of respondents including self-advocates, family members, providers, support staff, state/local agency staff and others. Some of the areas asked about included employment, health, housing, access to services and advocacy.



In-Person Survey

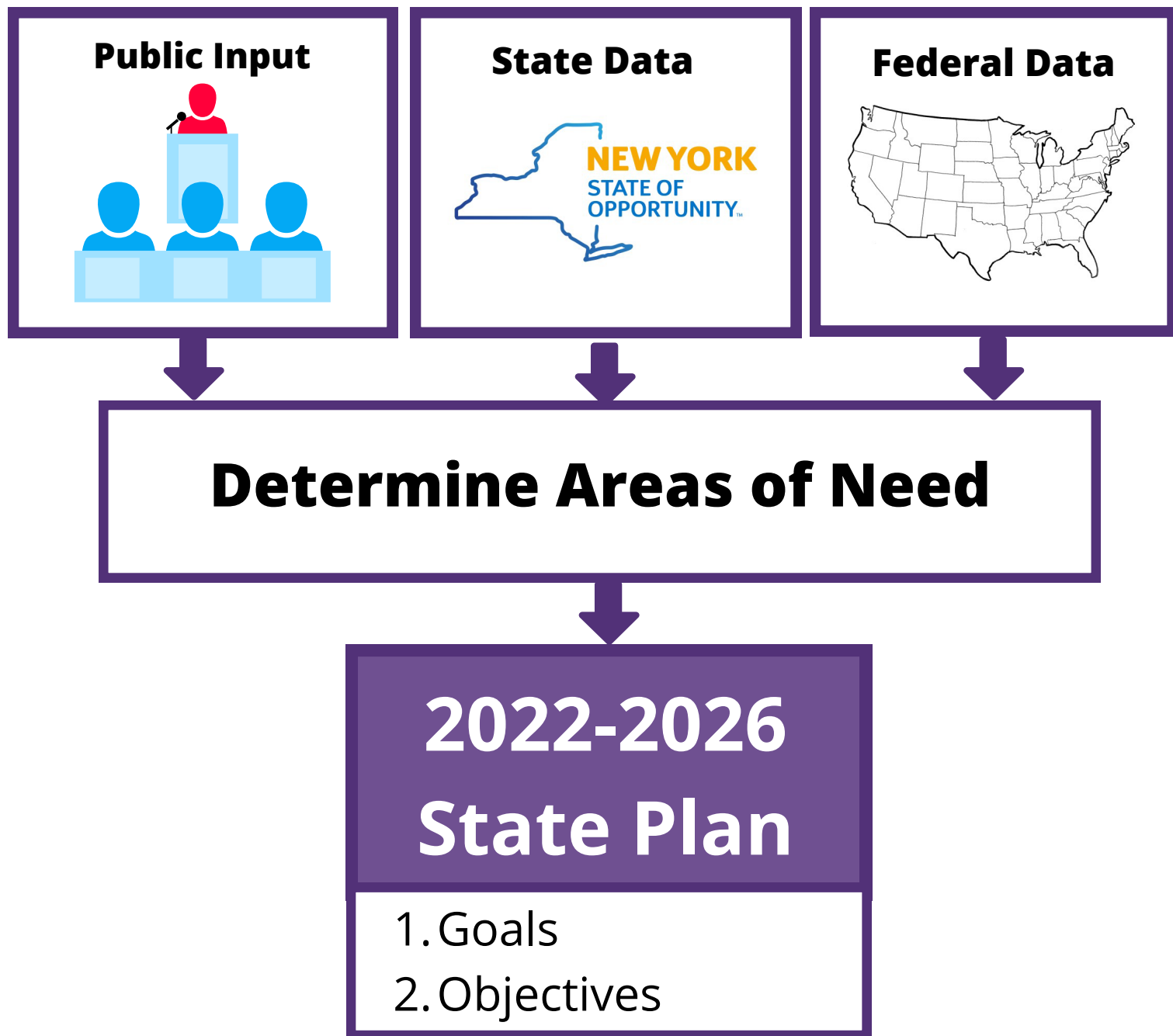
The DDPC also administered an in-person poll at the state's largest self-advocacy conference in the Fall of 2019. Over 100 self-advocates participated in the poll to identify key areas of work related to self-advocacy. Those that voted in the poll prioritized having more advocacy programs and resources to advocate in the community, with family and with staff.



Focus Groups

DDPC held eight focus groups with people in the IDD community from across the state. Several focus groups included representatives from underserved communities. The focus groups also engaged a few targeted groups that had lower rates of participation in the online survey. Focus groups ranged in size but totaled almost 150 participants.

State Plan Development: Research



The following provides an overview of the public input the DDPC collected, as well as research from federal and NYS data around these areas of need.



Employment

In the past decade, there has been a movement toward increasing competitive, integrated employment; closing sheltered workshops and raising sub-minimum wages. While the data suggests slight increases in employment of people with disabilities over the past ten years, they still continue to lag behind their working age peers without disabilities in terms of hours worked, wages earned and unemployment/under-employment rates both nationally and in NYS.

Data shows that people with IDD have a substantially lower employment rate than those without a disability.

Employment Rates	United States	New York State
People with a disability	37.8%	34.4%
People without a disability	80%	76.4%

Challenges to Successful Employment

1. Lack of access training opportunities
2. School-to-work barriers for students
3. Unemployment, reduction in work hours and barriers to working remotely.



Health Care and Well-being

Although over 95% of adults with disabilities living in New York have health coverage, people with IDD and their family members still report facing barriers to accessing health care. Lack of access to health care has led to health disparities, limited satisfaction with medical care and unmet medical needs, resulting in rates of chronic disease that are higher for people with IDD compared to the general public. This is especially true for people with IDD living in un/underserved communities. Many people with IDD also report having a mental health diagnosis. Research by the CDC revealed that at least 33% of people with IDD report feeling mental distress. In addition, respondents to the DDPC survey reported exacerbated mental health challenges due to isolation during the pandemic. State data shows that people with IDD in NYS have higher rates of chronic diseases, as shown below.

Health Risks	Percentage
Cardiovascular Disease	54%
Obesity	35%
Smoking	41%

Challenges to Accessing Healthcare

1. Lack of well-trained health professionals willing or comfortable with providing quality care to people with IDD
2. Language and communication barriers
3. High costs of care
4. Lack of accessible prevention programs and information
5. Lack of resources to serve dually-diagnosed people with IDD



Maintaining Services and Supports

COVID-19 made it clear that there is a need to re-evaluate NY's ability to meet the service and support needs of the IDD community. As the system transitioned to a mostly virtual model during the pandemic, people with IDD's experiences varied based on access to reliable internet and devices and the quality of virtual services. Some families struggled to balance participation in virtual services with the telecommuting needs of family caregivers that were working from home.

Family caregivers frequently filled support gaps when day programming and in-home services were shut down during the pandemic. During focus groups, family caregivers said this often came to their own detriment, negatively impacting their mental and physical health and employment. Family caregivers also reported feeling unsupported by the state. Self-advocates frequently shared that the closure of day programs made them feel isolated and had an adverse impact on their daily routines, skill-building and mental health.

The pandemic placed additional stress on a workforce already in crisis. Providers continue to struggle to attract new employees, retain existing employees (especially experienced ones) and maintain staffing levels that are sufficient to operate programs at full capacity.

Challenges to Maintaining Services and Supports

1. Disparities between communities' access to programs
2. Clear gaps in service for urban/marginalized communities, individuals living in poverty and rural communities
3. Disparity in access to technology devices and reliable internet
4. DSP staffing crisis worsened by COVID-19
5. Lack of supports for family caregivers

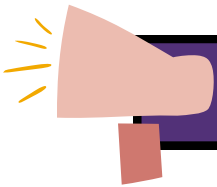


Housing

Research across the United States and in other countries show that people with IDD are likely to lead a better life when they live with fewer people in less congregated settings. The more people who live in a group home setting, the more likely that someone with a disability will feel lonely. Being able to live in smaller settings in the community is not only cost effective but leads to better outcomes for individuals with IDD. The ARC of the United States recently conducted a study where they found that the overwhelming majority of people with IDD and their family members wanted people with IDD to live in their own homes or apartments.

Challenges to Housing

1. A need to provide more education and information on the different housing options available for people with disabilities
2. A lack of opportunity for people with IDD to self-select their own housing options and roommates, as well as limited information provided directly to self-advocates about options and initiatives to assist with independent living



Self-Advocacy

Research and public input identified a need for continued growth in self-advocacy opportunities and training for both people with IDD and family caregivers.

Challenges to Expanding and Supporting Self-Advocacy

1. Lack of a strong advocacy voice and a limited number of people with IDD in leadership positions
2. Lack of support for peer-led advocacy/training opportunities



Preventing Abuse, Violence and Trafficking

It is reported that people with IDD are eight to ten times more likely to experience abuse and experience rape and sexual assault at much higher rates. Similarly, people with disabilities have nearly double the risk of experiencing intimate partner/domestic violence. These rates of abuse were exacerbated during COVID-19, as the state saw a spike in domestic violence and abuse/neglect reports.

Research also suggests that people with IDD are at higher risk for abuse because they lack education on sexuality, healthy relationships and abuse awareness. It also suggested that those living in congregate settings are more likely to experience abuse but less likely to report it. People with IDD, family caregivers and protection and advocacy groups have noted inappropriate usage of restraints and seclusion in some service delivery systems.

There is also increasing data that suggests people with IDD, including children, are increasingly becoming victims of human trafficking. In addition, people with IDD are at higher risk for being involved in the criminal and juvenile justice systems and tend to serve longer sentences than those without disabilities.

Challenges to Preventing Abuse, Violence and Trafficking

1. Lack of disability awareness by key members of the criminal justice system, including judges, attorneys and law enforcement
2. Inappropriate use of restraints and seclusion
3. Lack of awareness of resources for people with IDD, who are victims of abuse, including institutional and domestic violence
4. Lack of programs to teach people with IDD about human trafficking

From Research to State Plan

The outlined research directed a majority of the NYS DDPC's 2022-2026 State Plan, and the Council's overall focus to build capacity for community inclusion, advocacy and change in the lives of people with disabilities and their families. The Council will work in the following areas over the next five years :



People with IDD



Families and Caregivers of people with IDD



Systems Access and Change

Research identified several groups who face additional obstacles beyond those faced by people with IDD in general. Therefore, embedded in all of the NYS DDPC goal areas is a commitment to unserved and underserved populations.

Unserved and Underserved Communities Include:

- People with IDD and their families from racial/ethnic minority backgrounds
- People with IDD and their families who speak a primary language other than English
- People with IDD who identify as LGBTQIA+
- People with IDD who live in rural areas
- People with IDD who are aging (60 and older)

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Goal 1: People with IDD

The NYS DDPC will work to address barriers to community living for diverse people with IDD by expanding opportunities for self-advocacy and offering programs that help build skills for independent living.

Objectives:

1.) Self-Advocacy and Leadership

Increase the number of self-advocates and leaders with IDD by strengthening peer-led organizations, supporting opportunities for leadership and improving engagement of self-advocates in cross-disability and culturally diverse communities.

2.) Independent Living and Community Engagement

Increase opportunities for independent and community living for people with IDD by testing new programs that promote person-centered skill building and support independence, choice and meaningful participation in everyday life.

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Goal 2: Families and Caregivers of People with IDD

The NYS DDPC will increase advocacy opportunities and strengthen capacity of family members and caregivers from diverse communities to practice self-care and provide support to people with IDD to live independently and thrive in the community.

Objectives:

1.) Family Advocacy and Capacity Building

Support and expand opportunities to empower culturally diverse families and caregivers through increasing training in advocacy and leadership efforts and engagement in activities that help support family well-being and inclusion.

2.) Family Access to Information, Services, and Supports

Increase the number of training, education and outreach opportunities for family members and caregivers that improve access to services, supports and community resources.

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Goal 3: Systems Access and Change

The NYS DDPC will help to improve services, support, and systems within the state by piloting programs and supporting collaborations that promote person-centeredness, inclusion, disability awareness and outreach to all communities.

Objectives:

1.) Developmental Disability (DD) Systems

Decrease barriers that individuals and families face when trying to use DD systems, services and supports by making information more accessible/available, supporting inter-agency coordination and piloting projects

2.) Non-DD Systems

Increase the capacity for non-disability systems and organizations to support people with IDD and their families from all backgrounds by offering skill-building opportunities and technical assistance to make programs more accessible.

3.) Targeted Disparity

Increase access to information, services and supports for low-income (at or below poverty line) families and people with IDD by creating opportunities for community-based initiatives that reduce barriers to access and use of DD and community supports.

4.) DD Collaboration

Collaborate with the NY DD Network to help people, during points of transition, to plan for future needs and access to services by increasing availability of information, building community collaborations and educating people with IDD and families on their options.



**Developmental
Disabilities
Planning Council**

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